APPENDIX F
INSURANCE AND THE REIMBURSEMENT OF TRANSGENDER HEALTH CARE

INTERNATIONAL CONFERENCE OF
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INSURANCE AND THE REIMBURSEMENT OF TRANSGENDER HEALTH CARE

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I. Standard Exclusionary Language:

The focus of this paper is on the common exclusion of transgender health care procedures from public and private health care reimbursement programs. What do we need to know and to do to reverse policy's that exclude us? Lastly an attempt is made in the final section to offer some strategy's for achieving reimbursement on an individual claim basis regardless of the Payer's stated policy.

(A). Federal Acts:

Federal legislation has rarely provided protection for Transgender issues. The precedent established in the ADA to specifically exclude Transgendered people has been generally followed in the Health Care bills now being considered by Congress.

(1) President Clinton's Health Security Act in Part 4- Exclusions, Sec. 1141, (b) Additional Exclusions, (6), expressly excludes Sex Change Surgery and related services.

(2) The Senate Labor and Human Resources Bill (Senator Kennedy) adopted the identical language and code section found in the President's original proposal. The Senate Finance Committee did not address in it's Bill Part 4- Exclusions relying on the Labor and Human Resources Committee to adopt appropriate language. The Compromise Bills of Senator Mitchell and Representative Gephardt adopted the exclusionary language found in the President's proposal.

(3) HR 1200 (Representatives Conyers and McDermott.) The so-called 'Universal-Access' Act. This Bill did not get out of Committee. It is however unique in that it provided a General Exclusions section which did not specifically exclude Transgender Health Care. A Co-sponsor of this Act Rep. Pelosi (D-Calif,) wrote this writer to state that HR 1200 "would cover all medically necessary services, including those specific to transsexual health care'

(B). Private Health Care Coverages:

Private Health Care policy's commonly, but do not uniformly exclude Transgender Health Care. At present there is no clearinghouse of information detailing those companies with policies containing the standard exclusionary language from those that do.

I quote from two policy's containing commonly used exclusionary language.

> "(1) Kaiser Permanente, CalPers, HMO policy, August 1, 1994 — Sec. 5-A, Exclusions from Coverage, 13. Services related to sexual reassignment."
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> "(2) Take Care, CalPers, HMO policy , August 1, 1994 — General Exclusions and Limitations, A. Plan Exclusions, (33) Sex Change. Any procedure or treatment designed to alter the member's physical characteristics to those of the opposite sex or any other treatment or studies relating to sex transformation."

Comment: A reading of the contents of either policy raises questions as to the extent the exclusionary language contradicts other provisions of the policy contract. Most specifically those sections relating to Mental Health coverage's. Is an individual otherwise covered for psychiatric evaluation or treatment under the policy **excluded** from evaluation and treatment because the **condition** originating such care is related to sexual reassignment?

What is meant by the terms — "services related to"; "Any procedure or treatment"? Such language is comparatively very broad and sweeping. Perhaps sufficiently broad and sweeping to be it's undoing. Is it intended to exclude initial psychiatric care and evaluation as called for by the HBIGDA Standards of Care? Hormonal Therapy? Or is it intended to relate only to SRS procedures and those services?

What is the basis for such exclusionary language and can such language withstand judicial review? I can find no cases where the question of a refusal to provide any coverage for Transgender Health Care has been litigated against a private insurer at the appellate level. Nor have the appellate courts been called on to define what is an appropriate standard for services that may be excluded by the standard exclusionary language.

It is additionally important to for us to recognize there are times when no result is better than a losing effort. A case in point may be the Federal health care legislation. For Congress to enact legislation barring SRS related services would leave us with the need to overturn in the Federal courts a Congressional action, or to obtain a new majority in a later Congress intent on overturning prior legislation. Both are hurdles that are problematic at best for any group that is both small in number and under funded. Reversing administrative procedures and private policy language is one thing. Reversing an Act of Congress is quite another.

Silence can also be golden. Given it's context the silence of the McDermott/Conyers Bill served our interests quite well. In health care legislation we do not need a specific inclusion; but the absence of the specific exclusion.

II. Transgender Reimbursement Legal Issues:

In the late 1970's and early 1980's there were a number of important cases that addressed the issue of transgendered health care; specifically transsexual individuals, to be reimbursed for the cost of SRS. In each instance the coverage for SRS was sought under a state operated Federally funded Medicare program. These cases while not providing all that we might have desired did establish some important precedents. The applicability of these precedents to private health care coverage cases has neither been established or restrained.

(A). **Doe v. State of Minnesota**, (257 NW2d, 816. 1977). The Minnesota Supreme Court in Doe found that the Minnesota Medicare (MA) plan that provided for a total exclusion of transsexual surgery from

eligibility for medical assistance payments was void as arbitrary and unreasonable. The Court found that transsexual surgery was singled out for exclusion and therefore violative of federal standards that called for the state not to reduce benefits solely because of the diagnosis, type of illness or condition. It is also interesting to note that the Doe Court ruled out a standard that would equate medical necessity with a guarantee of surgical success.

(B). **Rush v. Parham,** (440 Fed Sup, 383. 1977) This case is one of two involving Carolyn Rush. Ms. Rush sought reimbursement for SRS under the Medicare plan for the state of Georgia. As in the Doe Court , the court found that the expressed language of the state of Georgia barring transsexual surgery was arbitrary and contrary to federal standards.

What was unique to the Rush v. Parham case is the court held that it was the responsibility of the **treating physician** and **not the state** to determine medical necessity. This court relied significantly on the distinction drawn between 'nontherapeudic elective procedures and necessary medical treatment' drawn by the US Supreme Court in Beal v. Doe. The Court did not find persuasive the state's argument that SRS was experimental, cosmetic, unsuitable or unavailable.

On September 15, 1980 the US Court of Appeals Fifth Circuit reversed the court's decision and remanded the case to determine (1) did the state have a policy prohibiting **experimental** services, and (2) was it's determination that **transsexual surgery is experimental reasonable.** The Appeals Court stated "we caution, however, that if defendants simply denied payment for the proposed surgery because it was transsexual surgery, Georgia would now be required to pay for the operation".

(C). **Rush v. Johnson,** (565 Fed Sup, 856. 1983). This is the single most important precedent case to the exclusion of transgendered people in health care. The issue here was did Georgia have a reasonable foundation for ruling SRS was experimental . The burden of proof to demonstrate that Georgia did not have a reasonable foundation had been shifted to Rush.

The Court noted the DSM as "an authoritative text which is an expression of the consensus of the psychiatric community as of 1980" that finds "since surgical sex reassignment is a recent development, the long-term course of the disorder with this treatment is unknown". Both plaintiffs and defendants introduced conflicting expert testimony as to the efficacy of SRS as treatment for gender dysphoria. Prominent among those testifying for the state was Dr. John Meyer of Johns Hopkins. Dr. Meyer had been active in the gender program at Johns Hopkins. He argued for a 'psychogenic origin' of transsexuality. He further found that his research (1971-1974) revealed little long term distinction between those who had undergone surgery and those who had not.

The court appears to have relied heavily on the evidence of Dr. Meyer in finding "substantial evidence presents a picture of growing concern in the medical literature over the long-term effectiveness of sex-reassignment surgery as a generally accepted form of treatment". The court concluded there was **no consensus** in the professional medical community. Given such a finding it was automatic that the court could hold that the state of Georgia was not acting arbitrarily to conclude that SRS procedures were experimental and therefore validly not reimbursable.

Coincidental to the proceedings in the two Carloyn Rush cases the Federal government was active in the research of transgender health care. Federal reimbursement standards for Medicare programs are the responsibility of the Health Care Financing Administration (HCFA). HCFA standards are not obligatory on private payers. HCFA goes to the substantial lengths to establish that it is not a research agency. It is nonetheless true that many private organizations give great weight to the standards set by HCFA in their own reimbursement practices.

Based on two studies in 1979 and 1981 HCFA has found that SRS is experimental and issued guidelines barring SRS reimbursement on that basis. HCFA has not addressed the issue of SRS or transgender related health care procedures since 1981.

The 1979 study was completed by a Phar.D. and a Phar.B.

Acting in part on these findings the Department of Health and Human Services filed an amicus brief in support of the state in Rush v. Johnson.

The 1979 study found "there are no definitive standardized diagnostic tests...available for evaluating the transsexual". The effect of psychotherapy on transsexuals was found to be mixed depending on the researcher. Interestingly, since it is perhaps the only issue two pharmacologists might be considered qualified to address, they found "Hormonal treatment....appears to be successful in relieving suffering in the transsexual patient ....Complications of hormone therapy in transsexuals have not been reported to any significant extent in the literature.'.

In commenting on the effectiveness of SRS procedures they find "the surgical component of the treatment of transsexualism remains, within the greater medical community, an experimental procedure...at the present level of the state of the art of transsexual surgery, the potential for incapacitating complications of the surgical procedure represents a greater risk of prolonging disability compensation than the primary disorder itself....there appears to be a greater incidence of complications for these procedures compared to the average incidence of overall surgical complications".

In addressing the efficacy of SRS they note, "it has not been determined whether sex reassignment surgery significantly lessens the incidence rate of suicide among transsexuals".

The most critical finding of the 1979 HCFA report is it's finding on the experimental nature of SRS. The researchers found," several recent medical publications suggest that transsexual surgery is still considered experimental, in that it is not known how many and what percent of the transsexual patients are 'cured or 'rehabilitated' by the surgical procedure. The informational data base developed for this project similarly does not support an unconditional departure from the experimental classification assigned to transsexual surgery. The basis for this observation is the almost total absence of published controlled outcome studies relating to the efficacy of transsexual surgery to the medical and emotional expectations of the physicians, therapists and patients involved in this area of medical treatment."

(D). **Pinneke v. Preisser,** (623 Fed 2d, 546. 1980). This Eighth Circuit US Court of Appeals decision remains one of the most important to transgendered people receiving appropriate health care. The state of Iowa appeared not to argue that SRS may be "medically necessary, but that it was more in the nature of 'cosmetic surgery'. The court found that the state "without any formal rule making proceedings or hearings....established an irrebuttable presumption that the procedure of sex reassignment surgery can never be medically necessary when the surgery is a treatment for transsexualism and removes healthy, undamaged organs and tissue. This approach reflects inadequate solicitude for the applicant's diagnosed condition".

The court further quoted from **White v. Beal**, supra, 555 Fed 2d, 1152, "that the regulations permit discrimination in benefits based upon the degree of medical necessity but not upon the medical disorder from which the person suffers".

This court did not address the issue that SRS may be experimental.

(E). **G.B. v. Lackner**, (145, Cal Rpt, 555. 1978); and **J.D. v. Lackner**, (145, Cal Rpt, 570. 1978). These two companion cases were decided by the First District Court of Appeal in California. They are significant in that they establish that SRS is **not a cosmetic procedure**. Cosmetic procedures are routinely barred under both private and public health care programs. Additionally they are barred without reference to the medical disorder a patient suffers from. Exceptions to the cosmetic bar is generally allowed where it is established that an underlying organic problem exists or in case of traumatic injury.

The court found in one of the wonderful passages from a court, to be "considered cosmetic requires that the alteration (of the skin) would be considered by the average prudent observer to be within the range of normal and acceptable appearance....The average prudent observer probably has no desire and will not observe what is under the skirts or trousers of either a pre- or post operative transsexual. It is not a generally recognized characteristic of transsexuals to move about in the public in the nude".

Comment: It is perhaps incredible that the last case of note relating to transgendered health care is now eleven years old. Where do these cases leave us? What needs to be accomplished to move the legal status of transgender procedures out of the early 1980's?

Doe, Pinneke, both Rush cases, as well as the two v. Lackner cases argue to the point that transsexualism as a **condition** cannot be singled out for arbitrary adverse treatment by Medicare authorities. That SRS as a treatment cannot arbitrarily denied reimbursement. There is in the US Supreme Court ruling in Beal v. Doe a presumption for reimbursement for that which is "medically necessary ".

We have perhaps become accustomed to (although certainly not resigned to) the employment law cases where to discriminate on the basis our transgendered status is afforded legal sanction. The law in the health care area while problematic remains in some important respects more promising.

The underpinning of the denial of SRS reimbursement found by the Rush v. Johnson court was (1)that state was permitted to bar experimental procedures, and (2) that the state had a reasonable foundation for it's determination that SRS was experimental.

It would seem what we need to do now is clear — we need a base of information that demonstrates that the procedures we seek are **not now experimental**. In accomplishing a legal goal what is needed is scientific evidence. Thousands of SRS procedures have been completed in the past eleven years. Transgender health care issues have grown beyond the single issue of SRS reimbursement.

This writer is aware of no procedures that compare with SRS at remaining in the limbo status of 'experimental' for decades. Insurance plans pay for procedures that have been demonstrated to be effective. It is our success stories, the skills of those provide who now both surgical and non-surgical care is the basis for demonstrating the appropriateness of the care we receive. They are the needed counter to the flawed and narrow studies of the 1960's and 70's gender clinics.

DSM IV addresses the issue of SRS only to make the most qualified of statements regarding it's prevalence. The latest version of DSM (1994) falls well short of recording the potential for and actuality of successful gender transition. What is perhaps most profound is what it no longer says that it is has consistently said since 1980 -- "that the long term outcome of combined psychiatric, hormonal, and surgical sex-reassignment treatment is not well known". In future legal cases it will more difficult for the DSM to be used as evidence to argue that SRS and related services are experimental.

In researching this paper I could find only an apparent absence of studies that argue against the effectiveness of hormonal treatments for transgendered people. HCFA's own report says it is effective. This begs the question of the can officials, in particular Medicare, sustain a denial of such treatments?

HBIGDA standards are certainly not bound by such findings. It is perhaps however germane to ask the foundation for their restrictive cautions regarding hormonal therapy? Is it based on scientific evidence or is it based on inertia and the positional power of the caregiver vis-a-vie the patient?

In Rush v. Johnson the debate within the transgendered community regarding SRS was used by the state as evidence to document a lack of any consensus regarding SRS procedures. I cannot say it strongly enough — to say a procedure is not for me; is a sacred individual choice. To say a procedure is not for anyone; is to work to deny others their sacred right of individual choice. Such a stand reflects a morality I fail to understand. And the practical impact of the reimbursement restrictions placed on SRS has been the extension of restricted payments for transgendered health care well beyond SRS alone.

III. Experimental Medicine Reimbursement Legal Issues:

As medical science advances at a rapid rate employing new, changing and quite expensive procedures coincidental with insurance carriers and other payers developing advanced and elaborate cost control mechanisms there has been a not very surprising collision. A collision of interests that is reaching the courts and the legislatures with increasing rapidity. These have not been cases involving transgendered people but they have much significance for transgendered people. Our procedures have been deemed experimental and the courts and legislatures are addressing the question of the obligations of payers for experimental procedures. Successfully challenging the experimental designation of transgendered procedures begins with an understanding of the law as it relates to experimental medicine.

While the body of law relating to transgender health care has involved Medicare programs in experimental cases the payer has been private insurance and HMO entities. With Medicare procedures the legal question has been their adherence to the Congressional enabling Act, specifically Title XIX. Title XIX provides standards that state officials are limited by in the application of reimbursement policies. Limits to reimbursement must be based on "criteria as medical necessity or those contained in utilization or medical review procedures". Under private plans the legal standard is one of "abuse of discretion".

The cases found to date have often involved very sympathetic plaintiffs; i.e., terminally diagnosed cancer patients. The April 1993 edition of the Journal of American Medicine reported in their survey of 17 cases from 1980 - 1989 involving unproven and experimental procedures that the plaintiff was successful in 14 of those cases. These were cases with jury trials. Plaintiff victories generally included both actual and punitive damages. A recent Los Angeles County case involving an experimental bone marrow treatment for a terminal cancer patient resulted in a record $89 million dollar judgment against Health Net of California. The case is now on appeal. The plaintiffs in that case were the family of a young mother who died of breast cancer following the denial of treatment reimbursement. The effectiveness of the desired procedure is a substantially debated topic within the medical community.

The appellate courts have not generally responded with the degree of sympathy found in juries.

(A). **Barnett v. Kaiser Foundation Health Plan** , (1994 WL 400819 (9th Cir.(Cal))). Mr. Barnett was a patient in need of a liver transplant. Kaiser had a plan under which Mr. Barnett was covered that excluded experimental or investigational procedures. Mr. Barnett in addition to requiring a liver transplant had e-antigen hepatitis. Kaiser denied Mr. Barnett on the basis that 1) the procedure was experimental and 2) that Mr. Barnett was medically inappropriate due to his hepatitis.

In evaluating Kaiser's actions, the court used the standard of "arbitrary and capricious...The touchstone of 'arbitrary and capricious' conduct is unreasonableness". The facts of this case provide a model for judging Payer actions. Mr. Barnett argued that for Kaiser to be both a financial beneficiary of a treatment denial and the arbiter of appropriate treatment was a conflict of interest. Kaiser was able to demonstrate that they had in place a Medical Advisory Committee that reviewed all liver transplant requests, that the committee acted on protocols developed by the UCSF Medical Center, that Mr. Barnett's hepatitis was an absolute contra-indication to transplant under the UCSF protocols, that the committee had authority to and in 120 of 250 requested cases had approved liver transplants, and that the committee was effectively shielded from the financial impacts of their decisions.

One of the more interesting comments in the testimony was that of the head of the Medical Advisory Committee that their criteria was under constant review "based on changing literature and views of the profession". (One gathers 'constant review', unlike with SRS, indicates a time-frame measured in increments of less than decades.)

The courts in upholding Kaiser's actions did not make a medical judgment as to the appropriateness of the procedure sought or it's applicability to Mr. Barnett. What the court found was that the decision-making process used by Kaiser was reasonable and based on medical judgment not financial concerns.

(B). **Boland v. King County Medical Blue Shield,** (798 Fed Sup, 638. 1992). Mrs. Boland was diagnosed with terminal breast cancer, she sought authorization and reimbursement for high dose chemotherapy with autogolos bone marrow transplant. This is a procedure classified by Blue Shield as experimental and denied under her policy which excluded experimental procedures. Mrs. Boland argued at length there was a conflict of interest implicit in Blue Shield's role. In the Firestone case (489 US, 115) there is precedent that a "conflict of interest must be taken into account when determining whether there is abuse of discretion by the administrator".

Blue Shield defined experimental in their contract in an industry standard fashion:

> "An experimental or investigational service or supply is one that meets at least one of the following: 1. Is under clinical investigation by health professionals and is not generally recognized by the medical profession as tested and accepted medical practice. 2. Requires approval by the Federal Drug Administration or other governmental agency, and such approval has not been granted at the time the service or supply is ordered . 3. Has been classified by the national Blue Cross and Blue Shield Association as experimental or investigational."

In deciding for Blue Shield the court was persuaded that within limits of reasonable discretion, Blue Shield was free to determine medical procedures to be covered. The court relied significantly on finding that the local Blue Shield Association in King County, Washington was financially independent of the national BC/BS association. That it was the national association and not the local association that was responsible for determining procedures to be experimental. And lastly that in making those determinations the national BC/BS association relied upon that which is "generally recognized by the medical profession as tested and accepted medical practice".

(C). **Jones v. Laborers Health & Welfare Fund,** (906 Fed 2d, 480. 1990). This is also a breast cancer casein which Mrs. Jones sought reimbursement for hyperthermia as a treatment. In Barnett and Boland the courts had held that the standard for judging "abuse of discretion" was the reasonableness

of the payer actions. In the Jones case the court held the payer to a far less stringent standard in holding that "in order to constitute an abuse of discretion a trustee's factual findings must be clearly erroneous" . Additionally the court would accept only that evidence which had been presented to the trustees in support of request for reimbursement. While they appear to reach different standards of permissible payer conduct both Barnett and Jones are holdings of the Ninth US Circuit.

(D). **Jacob v. Blue Cross and Blue Shield of Oregon**, (92 Or.App, 259. 1988). This is also a cancer case where plaintiffs sought reimbursement for Gerson therapy received at a clinic in Tijuana, Mexico. Plaintiffs could not present any medical evidence in support of their request and argued their case on contractual grounds. The court found for BC/BS. The case is of note for the definition of **Medical Necessity** as defined by BC/BS -- "interpretation of accepted medical standards in our service area, it **cannot be omitted without adversely affecting the patient's condition**". Secondly, while finding for BC/BS the court noted "Blue Cross does not have unlimited discretion to decide what is and is not covered. In determining whether a claim falls within the exclusions, it must apply the objective standards set forth in the exclusions".

(E). **Johnson v. District 2 Marine Engineers**, (857 Fed 2d, 514. 1988). Mrs. Johnson required a liver transplant for terminal liver disease. Her policy excluded by express language liver transplants. This case is of note because while the court applied the traditional standard of reasonableness in finding for the payer it is the only case I could find in which the court additionally found the financial impact on the payer was a legitimate factor in payer decision-making.

(F). **Cowan v. Myers**, (232 Cal.Rptr, 299. 1987). This is a Medicare case. It is significant for it's definition of medical necessity and it's determination of who properly should determine medical necessity. (This case did not involve transgendered plaintiffs, it is interesting though that the two cases most extensively analyzed are Pinneke and Rush v. Johnson. I recommend reading it for it's analysis of those two significant transgender cases).

Plaintiffs argued that it is the individual physician who should determine in each case what is medically necessary for that patient. The court rejected that argument, "regulations expressly permit the state to limit services on the basis of medical necessity. We are convinced the Act did not intend the physician to be the sole arbiter of medical necessity ...such a rule (would) result in inconsistent and unfair applications based on variations between physicians".

California regulations had defined medical necessity as "that which is medically necessary to protect life or prevent significant disability". Federal guidelines included the phrase after "significant disability" -- **"or to alleviate severe pain"**. The court found California regulations without force except that the phrase "or to alleviate severe pain" be added.

Comment: What does all of this mean for transgendered health care?

1. Transgendered people cannot be denied reimbursement based on our condition.

2. The most controversial or at minimum the most litigated transgender procedure — SRS — has been held by Medicare officials and by most private health care plans to be experimental.

3. Experimental procedures as a class of benefits may be permissibly excluded from coverage. That which is medically necessary may not be excluded.

4. The extension of the coverage exclusion from SRS to non-SRS transgender health care procedures; eg.s, hormone therapy, pyschological therapy; appears to be founded not on medical evidence or caselaw; but on unchallenged arbitrary Payer actions.

5. The courts have given to the payers the responsibility for determining what is experimental and what is medically necessary. It is a responsibility that is subject to judicial review based on the reasonableness of the decision-making process. Payers may not act in an arbitrary or capricious manner.

6. The courts have held regardless of express exclusionary language that to exclude SRS simply because it is SRS would be an unsupportable arbitrary action.

7. Determinations of what is experimental and medically necessary should be based of medical evidence in accord with recognized medical practice. Notwithstanding the finding in one case, such determinations should not be based on the financial impact of the decision on the payer.

8. To achieve reimbursement for medical procedures, including transgender procedures, a body of medical evidence must exist that defines accepted, standard and proven medical practice for a given condition. That is not an argument for any or all of the specific HBIGDA standards. It is an argument for **recognized standards** in the application of medical services to transgendered people.

IV. Medical Technology Assessment Practices:

The standard applied in determining is a medical procedure experimental is a three part test.

1. Recognized by the medical profession as tested and accepted medical practice.
2. Approval by a necessary governmental agency is not in abeyance or withheld.
3. Has not been classified as experimental by the payer.

How can we judge whether a payer is acting reasonably in making their determinations? Payers, public and private, increasingly rely on what has come to be known as "Medical Technology Assessment Protocols". The practice of developing such protocols is growing field employing medical, legal and payer expertise.

In the late 1970's and early 1980's when transgender challenges to reimbursement policies were finding their way into the courts payers were called on only to answer a two part question in determining is a procedure experimental — Is it safe? Is it effective? It was an orientation that was heavily weighted to the experiences of the provider. Providers and Payers have come in the past decade to recognize the limits of such an analysis. Most particularly the limits it places on the experiences of the patient. Meanwhile payers have certainly noted that new procedures with costs that are unlimited often have benefits that are quite limited.

From the New England Journal of Medicine, September 1990, with 'New Technology Assessment:'

> "safety and efficacy remains, but...(assessments) now encompass the measurement of effectiveness, considerations of the quality of life, and patients' preferences, and especially the evaluation of costs and benefits".

The focus of new assessment practices is on the **outcomes** on the procedures applied. The clinical, financial, and the quality of life that results from the application of the medical technology.

A modern protocol includes the experiences of the patient:

> "The health care system sometimes behaves as if the patient did not matter, the patient *is* the ultimate customer....Two fallacies abound in the health care community concerning information from patients. The first is that patient derived data must be inaccurate or certainly not as accurate as information gleaned from a physician.

> The second is that the only information one can obtain from patients is their satisfaction with the service they receive. Both of these notions are patently untrue."
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> Measuring and Managing Health Care Quality: Procedures, Techniques andProtocols. (1991) N. Goldfield, M.D., M. Pine, M.D.,M.B.A., & J. Pine, M.R.E.

In 1992, the Department of Health and Human Services sponsored a conference on the subject of "New Medical Technology: Experimental or State-of-the-Art". The conference brought together a number of disciplines and sought to provide definition to the process of answering the question — is it experimental? It is interesting to read the comments of in particular the payer representatives.

Blue Cross/Blue Shield uses the following Five criteria:

1. The technology must have final approval from a regulatory body.
2. There must be scientific evidence concerning the effect of the technology on health outcomes--that is, there must be some published evidence about the benefits and risks of using the intervention.
3. The technology must improve net health outcome. Does the person live longer? Is the quality of life better? Does it increase the ability to function?
4. Is the new technology as beneficial as current technologies?
5. Is net approval attainable outside of a research setting. We might stipulate that the technology should only be used in certain settings, but this will not stop the technology from being approved.

Susan Gleeson, Executive Director, Technology Management Department, Blue Cross and Blue Shield Association

John Cova, Ph.D., Director of Medical Technology Assessment, Health Insurance Association of America, stated that: "A change from experimental to state-of-the-art should also signify that there are sufficient objective scientific data to show that the new technology offers significant clinical benefits and advantages relative to other technologies used for the same purposes".

Comment: Technology Assessment is an area that is developing and growing. Today the assessments are being completed internally within Payer organizations or for them by third party's under contract. Providers, Patients and Payers have expressed dissatisfactions with this process. Some seek to place legal restrictions on how Payers reach their decisions. Others including some Payers would like to shift this responsibility to the Federal government. The President's health care proposal and those of the Majority side in both Houses called for the establishment of National Health Boards that would be responsible for determining what is experimental and what is not. Who and how medical reimbursement decisions are made are ignored by our community at our peril.

The opportunity presented to the Transgendered community by Technology Assessment Protocols are: 1) The process by which reimbursement decisions are made is being openly defined. 2) New Assessment procedures are more inclusive of patient experiences than prior procedures. 3) The new standard of effectiveness is the *outcome* achieved. Has the quality of life been improved?

This writer believes that the major impediment to the inclusion of transgender health care procedures within the context of commonly accepted reimbursed procedures is the absence of scientific research into the outcomes of commonly received transgender services. When one compares transgender health care to the industry standard criteria established by Blue Cross/Blue Shield affirmative answers are available to each criteria; except perhaps the second -- the published research outcome studies.

We need scientific documentation of our successes; in clinical terms and most importantly of all in human terms.

V. Individual Claim Strategies:

My profession is Claims Administration. I am not an attorney; and nothing here should be taken to replace or substitute for the necessary consultation with trained personal legal counsel when confronted with a dispute. Dispute and argument with Payer entities is not unknown; it is not however a given. We are referred to in health care as *Payers* for the obvious reason.

Rule # 1 -- Don't take no for an answer. No, is just the beginning of negotiations.
Rule # 2 -- Request in writing.
Rule # 3 -- **Insist on answers in writing.**
Rule # 4 -- For anything you pay for out of pocket; obtain a receipt and keep your receipts.

Does your policy contain the standard exclusionary language regarding SRS and related services? Look in the General Exclusions section of the policy contract.

If not. Congratulations!

Your issue is now simply demonstrating the medical necessity of your desired procedure. It is a task carried out by your Physician, Psychiatrist, Psychologist and/or therapist.

Key findings that to Payer organizations will indicate medical necessity are:

- Diagnosis, treatment and procedures conducted in accord with accepted and standard medical practice for this condition. Were HBIGDA standards followed?
  If so, that's very important. It is indicative of accepted practice.
  The absence of this procedure will adversely effect the patient's condition.
- Procedure or service is necessary to protect life, prevent significant disability, or to alleviate severe pain.
- Alternative methods of care were attempted and unsuccessful, eg.s,. psychotherapy failed to change the underlying condition. The requested care offers a greater opportunity for success than alternative care already delivered or now considered.

If your policy like most contains the standard exclusionary language all of the above regarding medical necessity remains important. What is added is the burden of overcoming the exclusion. It will not be easy; the odds are against you. It is not impossible. And it is a fight for care and reimbursements we are entitled to. No one asked if we were transgendered when we were making insurance payments.

Request each desired treatment separately — psych .evaluations; psych treatments; hormonal therapy; SRS; follow-up surgical care, genital, breast or other. I have heard of reports of transsexuals encountering difficulties with post-surgical follow-up care. I would be very suspicious of post-surgical denials. Let your physicians make the requests whenever possible.

Don't accept the answer — It's excluded by the contract. It is likely however to be the initial answer. Contracts are subject to review. It's their language. It is their responsibility to defend the language and the contract.

Very important; by contract or by state law — are there specified appeal and grievance procedures? If so, be careful to follow them. Watch deadlines; yours and theirs. Often missing a deadline waves a right — a right to appeal; and when the carrier is late perhaps the right to deny.

Inform them that you believe the contract language to be invalid. Ask what is the basis for the contract exclusion?

How do they define "SRS and all related services"? Why?

Do they deny as a cosmetic procedure? Refer them to Doe v. Minnesota, Rush v. Parham, G.B. v. Lackner and J.D. v. Lackner. (If you can watch their eyes when you do that!)

Do they exclude all transgender care by condition? Refer them to White v. Beal, Pinneke v. Preisser, Rush v. Johnson, and Doe v. Minnesota.

Do they exclude as experimental? If so, the strategy I am suggesting is to challenge the process used by the Payer in reaching that designation. Can their designation process for transgender care be shown to be legally deficient in comparison to the practices engaged in by Payers and condoned by the courts in Barnett v. Kaiser, Boland v. King County and Jacob v. Blue Cross?

Exactly what is being defined as experimental? Therapy? Hormones? SRS? (If everything related to sex transformation that is beginning to sound very similar to exclusion by condition.

How was the conclusion that it is experimental reached?

On what evidence?

When was the evidence last reviewed?

What literature was reviewed? How timely is that literature?

What are the qualifications of the personnel responsible for making the experimental determination? What experience do they have in the diagnosis and treatment of transgendered people? Was any medical analysis completed prior to the implementation of the exclusion? Was it an underwriting decision?

Are they familiar with the procedures requested? With the physicians who have performed or will perform the procedures? With their success/complications rates? Have they attempted to familiarize themselves?

Do they have a Medical Review Committee?

Was this request reviewed by the Medical Review Committee? Why not? On what basis does the Medical Review Committee become involved in an appeal?

Can/Does the Medical Review Committee make exceptions to the bar against reimbursement for experimental services? How often? On what basis? How often do they make exceptions where the patient is transgendered?

By what process does Payer's review procedures attempt to keep up with changes in medical practice? Have they used that process to track developments in transgender health care procedures?

Has a Technology Assessment Protocol of the requested procedure been completed? Insist on a copy. (And please send it to me, I'd love to see one on transgender care.) When was it done? Does it include patient experience as a criteria? Is there a plan to do an Assessment protocol? If so, when and on what basis are procedures denied while the protocol is being developed?

Sometimes, sometimes — if you're persistent, polite and a pest — they'll pay you just to go away! And other times it does not work. I simply refuse to believe we have accept these policies as a given. One of the reasons we are not included; is that we accepted it when we were excluded. It is a fight is worth taking on.

Reimbursement does matter. All the rights in the world to transgender health care; will not matter if you don't have the money to pay for that health care.